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ABSTRACT

The panel discussion looked at cross cultural aspects of community integration for persons with severe disabilities. Programs within West Germany, Israel, and Sweden are compared to the United States. Differences among countries in size, wealth, external pressures, history, and organization of services are noted. (DB)

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Cross-Cultural Perspectives on Community Integration and Employment : Israel, Sweden, the United States and West Germany.

A Transcript of A Panel
Presented at the 14th Annual Conference of The Association for Persons With Severe Handicaps

October 29, 1987

Carola Murray-Seegert (Chairperson), Inger Claesson Wästberg, Judith Cohen, Nira Dangoor, Dorothy Kerzner Lipsky, & Stefan Rothschild

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Cross-Cultural Perspectives on Community Integration and Employment

Carola Murray-Seegert

On behalf of my fellow panelists, and also on behalf of the Cross Cultural Committee of TASH - the Association for Persons With Severe Handicaps, I would like to welcome you to our 14th annual conference. This marks the third year that members of the Cross Cultural Committee have presented papers on disability issues in countries and cultures outside of North America. Today, we will describe and compare community-based programs for disabled individuals in Israel, Sweden, the U.S. and West Germany.

First, let me introduce the members of our panel. Inger Claesson Wästberg is a political scientist who was formerly a member of the Stockholm County Council and who is now Director of the Stiftelsen Institutet für Integration in Stockholm. She has recently published a report on family support services in Sweden, and is organizing the first international conference on family support related to disability, to be held in Stockholm from August 14th to the 18th, 1988.

Stefan Rothschild is Director of Residential Services for Akim, a private non-profit association begun by parents of disabled persons in Jerusalem. This year, he is spending a sabbatical year at Johns Hopkins University, studying community-based services and supported work options before returning to Israel.

Nira Dangoor is head of the Kibbutz Rehabilitation Center for Israel, an agency that deals with all aspects of special services to disabled persons living on Kibbutzim. She is substituting for Dr. Manny Chegier, who was unable to be with us.

Dorothy Kerzner Lipsky is both a special education professional and a parent of a disabled child. Dr. Lipsky worked for many years as an administrator in the New York City Public Schools. She is currently on leave from the Office of Sponsored Research - the Graduate School and University Center at the City University of New York. This year, Dorothy is the Mary C. Switzer Distinguished Fellow, National Institute of Rehabilitation Research. She recently completed a study of family services in Israel, sponsored by the World Rehabilitation Fund.

Judith Cohen is also an experienced special education professional and a parent of a daughter with disabilities. Dr. Cohen works at the Institute of Applied Human Dynamics in New York, and also does extensive volunteer work in Israel.

My name is Carola Murray-Seegert. Although I grew up in the United States, I have taught in Australia and Greece, and I am married to a German (who, by the way, teaches in Frankfurt's only academic secondary school that serves disabled students). I work for the Department of Defense Dependents Schools in Frankfurt, where I teach in a high school integration program serving adolescents who have severe disabilities. I am also working on a book on social relations between severely disabled and nondisabled adolescents, based on research I conducted in a San Francisco High School.

Now to the topic of our discussion: cross cultural perspectives on community integration. Since TASH first met in 1973, the organization's members have expanded our criteria for evaluating quality services for severely disabled persons. Not only do we value normalized, integrated school services for disabled young people these days, but we have also begun to realize that the broader concept of community integration should be our ultimate goal, whether we are family members, service providers, or simply friends of people with severe handicaps.

A commitment to community integration means a commitment to disabled persons' participation - no matter how severe their disabilities - in nonsegregative home, school, leisure and work settings. As Dorothy Lipsky says, central to this commitment is the concept that adapting the setting is a more appropriate focus for our activities than "fixing" an individual's impairment. Currently, TASH and other pro-integration organizations are asking questions such as the following: How can severely disabled individuals be best served in their communities? What are the economic incentives and disincentives affecting community-based services? How do governmental policies shape integration opportunities?

A cross-cultural, comparative perspective on community integration offers guidance as to how such services may be organized, delivered, funded, and maintained in the ongoing life of a community. While Germany, Israel, and Sweden are very much like the U.S. in terms of their levels of technological and economic development, and in terms of the sophistication of education and rehabilitation services available to disabled persons, these countries are also very different in terms of size, wealth, social policies, external pressures, and history - all of which affect the organization of such services.

Our presentation, therefore, is meant to assist in sharing information about service-delivery models, problems and successes in these countries. We hope to show how various programs work in practice, and to provoke thought about ways of improving the quality of life of individuals with disabilities in our different countries. After all our

panelists have spoken, there will be time for questions and discussion with audience members. First, we will hear from Inger Claesson Wästberg, from Sweden.

Inger Claesson Wästberg

I would like to give you a brief overview of the developments in my country, and then to show you a video tape that the County Council of Stockholm has prepared showing the change from institutionalized services to smaller, community based services.

Stockholm county is Sweden's biggest county with one and a half million inhabitants and an area of about 6500 square kilometers. Everyone living in the region contributes 14.5% of their income through taxes to the cost of the County Council's activities (individuals average 50% total tax payments on their incomes in Sweden). Of the County Council's total budget, 7% goes to the care committee, which serves about 5,000 individuals of all ages who have mental retardation and 1,700 children with physical impairments.

In 1975, a survey was made of the 5,000 persons with mental retardation and their needs - these needs were primarily related to normalization and integration - and a ten-year plan was made. The three main goals of the plan (1977-1987) were these: living in private homes should receive special support, family support should be given high priority in order to enable parents to maintain their child at home, and the percent of children living in their families should be increased from 62% to 76%.

A main feature of the family support system is respite care. Every district has a short-term home accommodating four or five children at the same time. Every family has the right to use this respite care for one week per month. This form of support can also be combined with a person paid by the municipality who comes to the home for a certain number of hours every week.

The changes in our service system as a result of the ten-year plan have succeeded. Eighty-three percent of children (age 0-16) now live with their families (compared with 62% in 1977). Nowadays, 90% of preschool children live with their families compared with 75% ten years ago. In the beginning of the 1970's about 2,500 children with mental retardation lived in institutions in Sweden. By 1986 there were only 400 children (0-18) in institutions, of whom less than 20 were under the age of 7 and more than 200 were over the age of 16.

(The audience then saw a professionally-made 20-minute video tape that presented an historical view of the development of services for mentally retarded persons in Sweden.)

In Sweden, day centers provide care 5 days a week. Work is usually organized in small groups. The staff provide training and supervision. The day centers are located in areas in the community where other people work during the day. Most usually day centers are organized to serve forty persons. Some are larger, some are smaller. In order to provide meaningful work for everyone it is necessary to find and develop many types of activities. Many adults who have not been assisted to complete schooling join adult education courses. Activities do not have to take place in the day center's premises. The endeavor to achieve integration means that the day activity center should be in close proximity to ordinary daily life in the community.

To enable mentally retarded persons to live in the community it is necessary for them to have access to special support if it is needed. This type of service is provided from a district office that has psychological, social, and medical staff. The task of the district staff is to work with mentally retarded persons in their normal life situations. They work together with family members, other staff at group homes, at schools and even with staff from other social services. Much of their time is given to coordinating and planning all of the various support services given to mentally retarded persons.

Carola Murray-Seegert

Thank you, Inger. The changes you describe are certainly enviable - particularly in the area of family support and financial resources available for community integration. I'd like now to speak about another aspect of community living, this time transition from school to employment in Germany. Germany is interesting to me for three reasons: it has developed a very sophisticated system supporting school-to-work transitions for nondisabled teenagers and those who have slight disabilities, it maintains a quota system coupled with economic incentives to hire the disabled, but it is, nevertheless, a country that has lagged behind its European neighbors in the provision of community based, non-institutional services for persons with severe handicaps.

The move towards normalized, integrated services for disabled persons began late in West Germany (in comparison to Italy, and the Scandinavian countries at least). For example, the country's first conference on the theme of "Normalization" was held just two years ago, sponsored by Lebenshilfe and the I.L.S.M.H. Wolf Wolfensberger spoke and Rosemary Dybwad (a long-time TASH member) was a guest of honor at this conference, one with effects that are still being felt in German disability services.

There is no single explanation for the fact that integration has moved so much more slowly in Germany than in

neighboring European countries. Historical, environmental, and cultural factors interact here, making disabled persons' access to mainstream society difficult. At the same time, the integration programs that do exist are models from which we in the U.S. could learn a great deal - about school reform for example. Let's discuss historical obstacles first.

Beginning at the end of the 1920's, Hitler and the National Socialist Party organized the campaign of "race purification" that ended with the Holocaust. Among the victims were an estimated 100,000 mentally retarded, mentally ill, and other disabled persons. During the reconstruction of Germany, after the second World War, parents of disabled children joined together to demand the construction of special facilities designed to educate, house, and protect their children. Their efforts were quite successful, and the organizations and institutions founded then still exist today - financially well-endowed and playing a powerful role in German disability politics - naturally with a strongly "protectionist" character that I see as supporting separation and segregation.

Environmental barriers also pose a severe problem for disabled persons and their families in Germany - as in other parts of Europe. In areas that were undamaged in the World Wars, streets, buildings, and public amenities reflect antique sensibilities rather than the access-needs of wheelchair users. There is no federal legislation of the sort that has assisted disabled persons in the U.S. by requiring barrier removal during renovation and the construction of new, barrier-free environments.

Public transportation systems - although newly expanded and remodeled in recent years in the major German cities - were not designed to accommodate persons with mobility limitations. An independent-living group in Kassel recently coordinated with the large San Francisco demonstration to protest that fact.

In consequence, disabled persons and their families tend to use private transportation or subsidized taxis. They also tend to spend their holidays in special houses paid for by private disability-help groups like Lebenshilfe.

Public attitudes towards the disabled are ambiguous - shaped, I think, by the fact that, due to the extent to which separate, special institutions are used by disabled persons, members of the nondisabled public rarely have contact with their disabled fellow-citizens. Although expressions of sympathy for disabled persons are quite common - for example, German television features a weekly program reporting in saccharine fashion on fund-raising campaigns for "die Behinderte" to which people give very generous sums of money (I have never seen such beautifully built special schools as in Germany) - the average citizen

is not so willing to have personal contact with people who have disabilities.

For example, a court in Frankfurt recently awarded damages to a couple who had booked a vacation through Neckermann tours, and who claimed that their holiday had been ruined because a group of disabled persons were sharing the same hotel facilities. They claimed that it was particularly distressing to have to look at them by the swimming pool and to share an elevator with individuals whom, they feared, might at any moment have a seizure. They won their case, and Neckermann refunded their travel costs.

The German educational system is one that sorts people out at an early age and tends to keep them separated throughout their lives. They have retained the system of examinations and tracked schooling that in American minds is more commonly associated with England (although England began moving away from this system towards comprehensive schooling some years ago). Beginning at the fourth or sixth grade, depending on what state you live in, students are sorted out by exams, teacher evaluation, and by parent recommendations into three tracks. Each track leads very strongly into a different level of professional opportunity and training, economic possibility and therefore social class status.

The structure of the German school system is important in the current discussion of school integration and vocational preparation for two reasons. First, because German parents are debating among themselves and arguing with the various state governments as to which of these various tracks should be integrated. Second, because integration, and the changes in pedagogical practices that are required as a consequence of the German integration model (cooperative, project-oriented lessons for example) is seen, by the Green Party and other school-reform advocates, as a means to improving schools for all children. These are complicated issues that would be subject enough for another presentation.

As you might guess, Germany has a highly specialized and segregative special education system. They have seven different kinds of special schools - separate ones for students with learning impairments, physical handicaps, hearing impairments, vision problems, behavior problems, and mental retardation. They even have special schools for students with speech impairments - children who stutter can be sent to special, segregated schools until the end of the 6th grade. Severely disabled students, unless they're lucky enough to attend an experimental integration class, attend special schools for the physically handicapped or mentally retarded where they can remain until their mid-twenties.

Those integrated services that are available to children with severe disabilities are, however of an

exceptionally high quality - when Germans do something, they tend to do it very thoroughly, and this is exemplified in their I-klassen or integration classes at the preschool, kindergarten and elementary school levels.

Young children are the most likely to be integrated in the German educational system. Currently, there are preschool and kindergarten integration programs established in every state in Germany. More recently, about forty elementary schools have begun "I-Klassen" or integration classes - there are about 100 of these classes nationally.

A German integration class uses a different pedagogical and organizational model than we're used to here in TASH and in the US. An integration class is similar to the one we saw in this Swedish film in that children are taken into neighborhood schools and served on a regional basis by the regular elementary school. That means that, regardless of severity of disability, if a child lives in that neighborhood he is served then within a regular class with appropriate support services. Therefore, if he is a severely handicapped child with vision and hearing impairments that child receives therapeutic support within the context of the regular class. The model we're familiar with in the US - disabled students served in self-contained classes within regular schools - is rejected by integration advocates in Germany as too segregative.

These classes are all started through teacher and parent initiative - not, in contrast to our U S. experience, in response to federal legislative incentives. Although the national ministry for education and research does support model efforts financially and some state ministries of culture also provide funding for extra teachers required under this model, German legislation is such that initiative must come from the community and parents. In addition, teachers within each individual school have the right, presently, to refuse to accept disabled children in their classes.

There isn't the strong federal support that we have in the US - the legislation that says that you must integrate or show why not and German parents do not have right of appeal to a Federal law as we do. Parents must work together with teachers in individual schools. What happens generally is that individual parents or small groups of parents find a school, approach the principal and teachers in order to locate some who are receptive, and then start these integration classes on a very small scale. This puts a lot of responsibility on parents and requires a lot of effort from parents with the effect that only people with a lot of resources and a lot of energy are able to get integration classes going in their communities.

Cultural values that interact with characteristic German thought-patterns also seem to have made vocational

integration progress more slowly in Germany than in other European nations. Stephen Hamilton, who recently reported on German vocational education for the Phi Delta Kappan (November, 1986), speaks about the characteristic German respect for thoroughness and order and explains the ways that these qualities are reflected in the German job-credentialling system.

To take even a relatively unskilled job - say as a sales-person in a clothing store - you must have a diploma and a certificate of practical training. Carpenters, plumbers, house painters, butchers, and other craftsmen must go through years of training and apprenticeships. In order to fit into this credentialling system, German adolescents participate in an multi-level vocational education process that governs the transition from school to work, and this is administered through the school-track they are assigned to.

Work training programs and licensing procedures reflect their origins in the organizational characteristics and training practices of medieval guilds. For example, you see in Frankfurt from time to time young people dressed in old-fashioned double breasted black frock coats with white buttons and wearing broad-brimmed hats strolling the streets. These are apprentice carpenters who, during a phase of their training, must travel from place to place taking whatever woodworking jobs they can find. Such crafts are still frequently kept within families from generation to generation, as are businesses such as bakeries, wineries, and farms.

Adherence to traditional job training procedures can pose problems for individuals with disabilities. Individual opportunity seems, to an American, to be much more limited in this more traditional society. Our new-world assumption (ill-founded in reality though it may be) that each citizen deserves equal access, equal opportunity, and an equal chance to make it is not assumed in Germany.

Support for competitive work, as opposed to sheltered workshop placement, for persons with mental retardation is in the beginning stages. Except for a very limited number of model-development projects (the two I know of are in Berlin and Darmstadt) the vast majority of teenagers and adults with mental retardation do not work in integrated community settings.

Sheltered workshops are big business in Germany. In 1983, there were 70,000 people in 350 workshops in Germany. These workshops are not only big business, they also tend to be very large. There is a great deal of money invested in these sheltered settings. Dormitories housing up to 200 people or so may be connected to each workshop, providing meals and housing at a cost of 60,000 DM per year or about 32,000 US per resident. That money is paid by the state. You can see that there are certainly a lot of resources

available in Germany, the problem is to redirect them to integrated rather than segregated services.

At the moment, employment for people with disabilities is regulated by the Schwerbehinderten Gesetz - the severely handicapped law. It grows out of the aftermath of World War I and like our rehabilitation laws was first designed to take care of the disabled veteran. It still best suits the needs of persons who have become disabled through some accident or illness and who need prosthetic equipment, training or other support in order to retain or reenter occupations they held before they became disabled.

Businesses in Germany operate under a quota system with respect to the employment of disabled workers, and in this are similar to those in other European countries. The way this quota system works is that by law, 6% of the employees in any business should be defined as disabled according to the criteria set out in the Schwerbehinderten Gesetz. this means that they should have lost 50% or more of their functioning capacity. Employees hired under this 6% quota have tenure status with their firms, they receive 6 days extra holiday during the year, and there are certain provisions against their discharge. If the employer wishes to discharge one of these employees, he must show cause and prove that the discharge is due to some factor unrelated to the disability. However, there's a loophole in this which is that if the firm doesn't make their quota on this, they may pay the state 100 dm (about $60.00) per month per employee - for each person that they haven't hired. This fine is not so severe. About one third of all employers that were surveyed in 1983 preferred to pay the fine rather than employ the disabled persons.

If, as I have on several occasions, you interview someone who runs a sheltered workshop, they will tell you that this protective legislation actually makes the employer afraid to hire the disabled person because of all the special provisions against being fired. However if you ask an disabled person, they will say that this is just an excuse - you have to show cause if you fire any other tenure employee. But that's the way that it's used. Another interesting aspect of the quota system is that the employer may be forgiven one-third of this fine if he gives contracts to sheltered workshops. Sheltered workshops manage thereby to get contracts from businesses like Mercedes-Benz and Opel, but this acts as a financial disincentive to integration and a conscience-sop to large businesses.

In spite of these obstacles, things are looking very positive for integration in Germany. Over half of the 100 I-Klassen started in the last three years. There is a very influential and vocal new group in Germany called Eltern für Integration. They have a membership in TASH and are very interested in contact with our group and with learning more

about our experiences here. I have a handout listing resources in Germany, and after this panel is over, if you are especially interested in our situation there, please come see me and I will give you a contact address for this group.

The creation of successful integration programs for young children puts pressure on later service-providers. When your child has enjoyed attending an integrated elementary school and you're faced with the possibility of having to return that child to a segregated setting after elementary school, you then tend to fight very hard for integrated services at the high school and the vocational levels. This is what's happening now in Germany and I predict that in the next few years we will be seeing some very interesting programs for work support.

Germany is an interesting place to be. For example, their long-standing emphasis on thoughtfulness and planning works out to the advantage of these integration classes, some of which are pedagogically more radical and much better integrated than anything I've seen in the United States. On the other hand, it's a society governed by long standing formal and informal controls, and a history of extreme intolerance towards many minority groups - including the disabled. The status of disabled persons is presently in flux. There are some good resources there, and I would recommend that anyone who is interested in making contact with special education colleagues or parents of disabled children there speak to me after the session.

We have two visitors with us from Israel: Stefan Rothschild and Nira Dangoor. Stefan, would you tell us what you're doing in Israel with AKIM?

Stefan Rothschild

I'm actually Swedish-born, and that's why you may have heard me talking to Inger in Swedish. I moved to Israel in 1969 and got a Masters degree in Social Work from Hebrew University there and have been working since 1978 planning community services for disabled people in Jerusalem. I'm in the States as a Hubert Humphrey fellow in the School of Public Health at Johns Hopkins University in Baltimore until next summer, and then hopefully much more knowledgeable, will go back and continue.

I do not represent Israel in terms of any mainstream activities for the disabled, I represent one relatively small group in Israel working with community-based services and I would love to start by telling you about that, because I think that we have a really good project, but it wouldn't be fair to tell you about that without telling you about the general situation in Israel. I will describe these briefly, but I would also like to refer you to the report that Dorothy Kerzner Lipsky has written about her visit to Israel

two years ago. You may also talk to me after the session if you have more questions.

I will focus on those persons identified as severely mentally retarded in Israel - about 15 to 17,000 people. The main criterion in Israel is still IQ - in the 70's or below. There is a tendency to get away from these measures to more functional descriptions, but this is still the main way that people are classified. Of these 15-17,000 people, one-third are institutionalized. If one wishes to classify these institutions, one can do it by who runs them. The State institutions have about 60% of all institutionalized people, and the average size of those institutions is about 260. The private institutions have about 24% of all institutionalized people - their average size is 94 persons. Then there are institutions rub by private nonprofit organizations - about 16% of all institutionalized persons live in these. Their average size is 42.

The two things one can say about Israel in general are that most people who are institutionalized are typically in large institutions, and usually far away from their homes. When a family reaches the point where they have to seek a place in an institution for one of its members, they make an application for a place to the local social agency - there is one person there who will decide where this disabled retarded person will be placed and that could be anywhere in the country.

There is often a long, long wait for a place, and this may influence a family to accept a placement in an institution far away from the home. Now you may say that this is not such a problem in Israel because it is such a small country, but it IS a big problem even in a small country, because it means that to visit the disabled person or to deal with a problem, parent(s) and other family members may have to take a day off work and travel - say from Jerusalem to Accra or Demona - this takes a lot of time and also costs a lot of money, in relative terms.

We did a small survey seven years ago in Jerusalem. In Jerusalem there are 1,350 persons who are known to be mentally retarded of all levels of functioning - not including these groups among the Arab population among whom there are also lots of retarded persons who have not been systematically surveyed or diagnosed. One of the outcomes of our survey was that we found that families typically will visit their institutionalized member and the disabled person will visit home a lot during the first two years of institutionalization and then it drops from the third year on. Visits usually only occur once per year thereafter.

As an example of this, we have in Jerusalem a large institution called the Swedish Village because the houses were donated by Sweden. They have about 250 residents there - right in the middle of the city - but over 90% of the

residents are not from Jerusalem. At the same time, there are about 450 Jerusalemites - retarded- living in institutions OUTSIDE of the city.

This gives a rough idea of what is going on in general. Now I'll describe our program. I work for AKIM. It's a parent organization, a nonprofit organization. I'm responsible for the residential facilities. The city of Jerusalem has probably the most comprehensive resources for disabled persons, compared to other cities in Israel - mother/child clinics, child care facilities, child development programs, schools, hostels, apartments, recreational programs, and sheltered workshops. Many of these are operated by Akim with one exception which is the sheltered workshops that were opened two years ago by the Elwyn Institutes of Philadelphia - a fact that this audience may be interested in.

Akim has been trying to create an alternative to institutions - in terms of principles that guide us. We, as in the Swedish example you saw, are trying to get away from the big institutions, and we try to help parents to bring people back home who have been living far away, out of the city. We presently have eight apartments and two hostels with all together 100 residents, located in typical residential areas of the cities.

Now, what I might say that is true for all the people in Israel is that we have been under terrific economic strain. We have, nevertheless, a good network of social services and supports. However, no matter how fancy our network, our system is just not equipped to care for those persons with the most severe disabilities and behavioral disorders, and therefore needs reevaluation. What <u>does</u> stand out whenever I am talking about the Israeli scene is that we have no problems with neighbors in our residential facilities. In contrast to what I have heard about other countries, we do not encounter neighborhood resistance in any form - that really differentiates us from the U.S., for example. I don't really know what to ascribe it to. I think that there is threshold where we could encounter resistance - if we put in a much larger residence in some of the neighborhoods I think we could encounter problems - but we don't have so many zoning regulations, we are attentive to reactions, but that's it. To say that we have been successful would be to ascribe it to us, which would not be accurate. We have just encountered no problems.

On the administrative level, a great problem is that there is no mechanism for transferring funds from the institutional sector to the community. This is something that some of you may be familiar with, and there is no solution for it at this point. You cannot just close down a wing of an institution and take the money saved and transfer it to supported services with in the community. Rigid

bureaucratic rules don't allow it to happen. If we could get a lot of parents and advocates screaming about it and bringing media pressure to bear it probably could be changed, but so far that hasn't been done.

It is probably interesting to mention that in Israel it is relatively difficult to turn services for the disabled into a national priority. Because of the security situation and all the other problems the country faces, these services do not receive as much attention as they deserve. We need to reevaluate what is going on there.

Within our smaller network, there are a lot of cross-cultural things going on. In our committee meeting this morning, I discussed with Carola writing a description of this for the next TASH newsletter. There is a lot of contact between Jewish and Arab staff members and residents, religious and non-religious, ...we also have a lot of German volunteers who opt to work in our institutions instead of going into agriculture, and it's interesting to see the kinds of relations that develop through cross-group contact in these situations.

For example, we had a father who was not going to allow his daughter to move into one of our apartments because we had an arab staff member. The whole process of how we overcame that, and the outcomes which included the fact that the father is now in much more contact with his daughter than he ever was before the situation arose - initially he agreed to let her try this living situation and then he wanted to visit to check up on this worker whom he thought was going to do all these terrible things to his daughter, but now that his fears about that have disappeared, he just comes in because it's nice to visit - nice to be with her. So it's nice to talk about the success stories that happen in Israel also. They can be brought about, but they're still not the mainstream trend in services to persons with disabilities.

Carola Murray-Seegert

Thank you Stefan. It is indeed interesting to contrast the neighborhood acceptance you describe with the difficulties we experience in Germany and the US, and to speculate as to the origins of this tolerance. Nira, would you like to continue?

Nira Dangoor

I will try. I am not sure how familiar you all are with the concept of a Kibbutz and with what the Kibbutz life is. I represent the Kibbutz Federation Movement, which is like 4 or 5% of the population in Israel, or about 120,000 people all over the country. I work in the Rehabilitation Clinic which is one of the services of the Kibbutz Federation

Movement, which means that the clinic and services are funded by the Kibbutz movement, and not by the government or by any other source. We serve only families that are living in Kibbutz settings. Because of our private funding, we are able to give much more expensive services than are typical for Israel, even more costly than those provided by the Veterans Federation which is the richest rehabilitation service in Israel.

We have 280 Kibbutzim spread all over Israel from North to South, from East to West. Each is a relatively small, relatively closed community. The average population of each is four or five hundred persons of all ages, so we are talking about little communities. They are self-supporting economically. All social or educational services are given inside these communities - that means also social and educational services for disabled persons. In the Kibbutz, we have social obligations to each member of our community. Even if we have only one retarded child or one mentally ill person or one old person who is sick physically or mentally, we try to support all these people INSIDE the individual communities, with minimum referral to outside services or outside institutions. As much as possible, we try to supply all the services - even if it means two or three persons for one little child in a single school or kindergarten we are still trying to do it - even in the most severe cases.

I guess that in this our services are unique. Maybe because we don't have to ask for funding, that's why we can do it. It is seen as a social obligation of the community to assist each of its members and all the families living in the community.

Because of this social policy, the rehabilitation services try to solve transportation, housing, and work adaptation problems - everything that we do we try to solve within the community and not to refer to outside agencies. For special education services, we may send children out to special day care programs, or two or three Kibbutzim may share responsibility for these programs, but usually in the afternoons the child goes back to his or her community and that is where we try to develop social support and respite care services for the families. We are much better developed in the education part of our services - we are just beginning to develop the other kinds of support.

What is also unique in the Kibbutz movement is that older people do not necessarily retire. If you are 70 or 80 or 90, you still work if you want to work. This means that we as a community, as a movement, we are obliged to give all that is needed to give them opportunities to work. We are much more concerned to give people the opportunity to participate in the small industries and factories than is typical elsewhere. It is quite common to see people who are

70 years old and wheelchair users who are going to work every day.

Carola Murray-Seegert

Thank you, Nira. I knew that Kibbutzim were very different from the kinds of social settings most of us are used to, but I had not realized the extent to which these communities were equipped to deal with problems associated with disabilities. Now from Israel to the U.S. - Dorothy Kerzner Lipsky and Judy Cohen.

Dorothy Kerzner Lipsky

The information I have heard at this conference about what is happening both here in the United States and in other countries has certainly whetted my appetite to know why we're moving so slowly here in the U.S. For example, when talking about Sweden, it always amazes me that when Inger talks about a "large institution" she is talking about one that houses 7 to 14 people - in terms of deinstitutionalization, that society is quite a distance from where we are. The commitment of the government to community integration is really what seems to make the difference.

By the way, Stefan mentioned the report I edited, which is titled Family Supports For Families With A Disabled Member, and if anyone is interested in a copy of it, it's available from the World Rehabilitation Fund, 400 East 34th Street, New York, N.Y. 10016. It contains reports on family support services from England, Sweden, Israel, and Canada.

Let me first give a general definition of community integration, and then I will speak about the way this concept functions in the United States. As I see it, community integration is both a discrete concept as well as an umbrella-term used for a variety of activities. Overall, it draws from the concepts of normalization and the empowerment efforts of the disability rights movement. As a discrete effort, it has parallels in education in the concepts of mainstreaming, Least Restrictive Environment, and community-referenced curricula; in employment, in the premise of the supported work concept that adapting the setting is more central than "fixing" the impairment; and in much of the work of the centers for independent living.

At its core, community integration has a concept of right and entitlement, as well as benefit. The federal district court's order, in a recent class action suit in Oklahoma, Homewood Bound v. Hissom Memorial Center, sets forth a set of principles which express these rights:

- All persons are capable of growth and development.
- All persons deserve to be treated with dignity.
- All persons have value.

- All persons must be involved in and carry the primary responsibility for the decisions that affect their lives.
- All persons should live and work in the ;most natural setting.
- All persons should live in and be a part of the community.
- All children should live with families.
- All children have the right to a free and appropriate education.
- All citizens have the right to full exercise of their rights as guaranteed by the Constitution of the United States.

As these principles indicate, community integration both involves rights and a variety of service areas, including education, employment, housing, and cash benefits, as well as family and social networks. In each area,, the concept of control - individual autonomy - is key.

Within this framework, there are two complementary principles that affect human services practices. The first is that persons do not need to "earn" the opportunity to live in the community nor to "prove" their capacity to do so. Not only is it their right, there is also increasing evidence that "normal" settings encourage "normal" behavior. (There is substantial research as to this effect in educational "mainstreaming" programs, as well as increasing evidence in community-integration efforts).

The second principle is captured in the recognition that impairments become disabilities in the context of an inaccessible environment, both physical and attitudinal. To put it the other way around, an accommodating environment facilitates community integration. In education, this is seen in the adapted curriculum efforts. In employment, in the provision of supports to enable persons with disabilities to work in competitive settings. In transportation, in the provision of accessible public transportation. In housing, in the construction (or retrofitting) of accessible facilities - and not just a few units, for the goal is for persons with disabilities not only to live in the community but to be able to visit with others. In everyday living, there is the provision of personal assistance. This, in developing community integration programs the starting place is not the individual's impairment but rather the goal of community integration. And the first program design question then becomes what are the ways the environment must be modified in order to assure effective community integration.

Tom Bellamy has pointed out that too often when we plan to meet the needs of persons with disabilities our first inclination is to establish a separate system rather than

refashioning the regular system to serve all people. Thus, for example, special transition programs are established rather than building on the fact that most people find jobs through networks of family, friends, and acquaintances. So, too, it is as concerns community-integration.

Both goal and strategy must be to reject the view that community integration of persons with disabilities is special. Rather, it must be seen as and become the normal state. To do this we must, for example, stop building public spaces which are inaccessible - as if to say "No crips here" - and then fighting for a few curb cuts. Rather, in all our work, we must build for inclusion,, to expand the mainstream, to refashion what is seen as normal. Then, we will be able to achieve,, indeed will have achieved, community integration.

In terms of the way that community integration is currently realized in the U.S., I'm just going to say very briefly that my philosophy has to do with government, and that we have not yet painted a picture of what community integration means in the U.S.

We have a lot to do when we think about the individual in a center and the attitudes and the belief system that influences that kind of segregation. I think of the term "community integration" as really a broad umbrella concept covering both our education system and our rehabilitation system. We have not really integrated the most severely disabled students into our schools and classrooms, so it is not surprising that we have not yet integrated our communities in terms of our work environments and our living environments.

I know that where I come from in New York they're still burning down community residences - when they hear that the state Office of Developmental Disabilities wants to build a community residence in a nice white suburban middle class area, people still want try to go in and burn it down. It's the "everything is fine so long as it's not in my back yard" syndrome. Here in the US we haven't really gotten so far as to truly believe in integration as a goal and philosophy. I believe there are tremendous amounts of prejudice against persons with disabilities in our society.

In the employment area, integration is also moving very very slowly. I think of my own son Danny who is now 18, and beginning that process. He is one reason why I'm so interested in transition issues. Through the Switzer Fellowship, I'm looking at employment issues from multiple perspectives: from the employer perspective, the consumer perspective, and the service provider perspective - what strategies are successful, which are not, identifying the gaps in services, and then figuring how to close those gaps. Danny was placed in an employment situation through his high school and we had high hopes that this could really work

well. But they though that they could just PUT him in that job without supplying the kinds of continuing supports that were essential - that was a next step that just hadn't been thought through. His classroom teacher found the job for him, which is to her credit, but his employer didn't really understand what Danny's problems were as well as his capabilities. Danny, who is learning disabled as well as physically disabled, was too embarrassed to ask "What am I really supposed to be doing here" and "What does that really mean" and he didn't have a buddy to ask, (whom they should have paired him up with). So before three weeks was up, Danny was fired.

Well, that was a trauma for Danny personally, so we started trying to find out what had gone wrong. We called his teacher - Danny is mainstreamed and he has a resource room special education setting as well - and it turned out that she had never really talked to the employer about the fact that Danny had spasticity in one hand, and that there were some other things that could have been done to make this successful. Within our school district, it seemed that there really wasn't a clear picture yet of how to do all this. What was also lacking was a basic <u>commitment</u> to creating job opportunities for young people like Danny. The feeling that we should do it, not just because there's a parent pushing but because it's our belief system. There seemed to be no clear vision of HOW and WHY to do it all.

At home, at first, it was "Poor Danny, and how could this happen," but after discussing it we realized that - hey this could happen to anybody. My daughter told him how she had gotten fired because she hadn't scooped out the ice cream fast enough at Friendly's, you know, and it became a family discussion. We can't protect our kids, you know. If we really WANT them to be integrated, then we have to let them have some of these lumps also. It is part of living, but we also have to try to build as much as we can so that we prevent these sorts of things from constantly happening.

<u>Judith Cohen</u>

I'm also a parent and an educator and my child is profoundly handicapped and lives at home. Living at home in the community means that I want to know how to change people's attitudes. Can you change people's attitudes, or do you have to accept these attitudes? That is, if you can't live with people's attitudes then you have to change them, but how do you go about it? To quote Seymour Sarason: "To help integrate disabled people into the social world in which we live, society has to give them the best it can."

How does society give them the best it can? I feel personally that it is through education - you have to educate society to look at a person as a person. You should not see someone only in terms of his wheelchair or her

handicap, you should see them as a person. Look at her as a person with beauty inside and beauty outside. Look at what talents they have - what they can do, what they can contribute, how they act, what's nice about them. Ruthie, who can do nothing, has magnificent brown eyes - they're beautiful - and she sort of talks with them.

It's so important not to be isolated. The more that people see that disabled people are there, the less fear they'll feel - they won't cringe and think "oh my god, that's an animal out of her cage - put them back in." The more the public sees disabled persons, the better.

We found that taking our daughter every week to a certain restaurant helped. At first, they put us all the way in the back and wouldn't bother about us at all, but after a while, going every week, the waitresses were very nice, we noticed that the same people came into the restaurant and they began to say "oh how are you, did you have a cold last week, how are you feeling?" I mean, they started to accept. So I think that by seeing, by educating, that's a beginning.

Carola Murray-Seegert

Thank you, Judy and Dorothy. I think that for us in the TASH organization, those of us who attend a conference like this one, we probably have more than the average person's contact or more than the average acquaintance with disabilities -- either through family contacts, professional contacts, or through simple friendship and acquaintance. Sometimes it's hard to remember that the rest of the world out there isn't so well acquainted with disability as we are.

There's a theme that runs through these remarks that you've made - the theme of history. The history of what has gone on in our societies affects the cultural perceptions of people who are disabled. The video tape that Inger brought was unusual and very special in that it emphasized the economic strands in our attitudes towards disabled people - the ways in which societal change from an agrarian to an industrial society has had an effect on the ways in which people with differing abilities are treated and perceived.

This economic theme was also apparent in your remarks, Dorothy. In this era, in modern society, individual identity is more clearly determined by work and associated economic standing than ever before. It therefore becomes crucial to find ways to assist and support disabled young people in finding valued employment - and to follow-through on such efforts. Administrative support, in terms of staffing patterns that might make it easier for a teacher to go out and follow up a job-site placement, also depend on budget and economics. Financial considerations are also an issue that may deter an employer from wanting to involve himself

with a disabled employee as in Germany where there are financial incentives and disincentives.

Another theme in the panel's comments has to do with political policy. Political support - assigning social services a high priority - makes the Swedish situation possible. The history of a country such as Israel which has so many citizens who have become disabled through involvement in conflicts - disabled veterans having the ability to appeal to average citizens for support - this means that rehabilitation services have a powerful voice, although, judging from Stefan's comments, this power does not prevent mentally retarded persons being institutionalized and separated from their families.

We look at the potential for community living and employment in our own or in other cultures and we have to realize that it's not a simple linear arrangement of first exposure, then learning, then change, then everybody's happy. It's more an interlocking model - an ecological system - in which economics, history, culture, family patterns, and political reality interlock - affecting one another.

Culture changes slowly. Anthropologists document these changes in small societies and in our society too - societal institutions and individual belief systems resist change, for the most part. I believe as you do, Judy, that it's an act of political change and an act of cultural change to be out and about in public when you are severely disabled - to contact people in stores, to sit next to someone in a restaurant, to vacation in a hotel - but these changes occur slowly and through persistence and good will. Through conferences such as this one, as well, I think that we are supporting that change.

Dorothy Kerzner-Lipsky

Let me add just one other thing. If all of us in the areas in which we work realize that these changes must come about, then we all must, in our own professional areas, become advocates. We have to become politically sophisticated in order to get funding to do what needs to be done. For example, right now, there is a bill that will allow changes in Title 19 which would allow more funding for severely disabled individuals who are living at home. It would make a significant difference, and now that bill has been considered a number of times but it is always defeated. We have a lot of work to do! We cannot just believe that all this will just automatically come about - we must work within the political framework.

The other thing is, if you are interested in reading abut independent living, the Journal of the Association for Persons With Severe Handicaps had a very good article in 1986 (volume 11, page 236) by James Budd and Judy Bachelder at the University of Kansas on this subject. I would strongly recommend reading it.

Carola Murray-Seegert

Are there any questions or comments from the audience?

Betty Dillon

I just wanted to give an example to illustrate the close connection between economics and work-place integration. In Ireland, things were going very well for a while, but recently the economy has taken a downturn and unemployment has risen drastically, and so outside employment of the mentally handicapped has gone down twice as far and twice as fast as that of the nonhandicapped. This is because people say "You're laying off MY son who is able bodied and yet you're giving a job to this person who is mentally handicapped?" They cant push it as hard as they could have before.

Carola Murray-Seegert

I think it's important to note, as you said Betty, that the disabled were let off twice as fast. Robert Gaylord-Ross, a professor at San Francisco State and a TASH member, was a Fulbright Fellow in Europe last year and did a survey of employment for disabled persons during which he visited Germany and Switzerland among other countries. Very often in Germany, he heard this argument: "our unemployment rate is so high - it's around 10% - how can you expect us to be getting jobs for the disabled when nondisabled people are out of work?" He found that in Switzerland, where the unemployment rate is much lower than in Germany, that there were comparable proportions of mentally retarded persons in sheltered workshop facilities. Now, you would think that, if it were directly correlated with the employment rates, that Switzerland would have had a higher proportion of disabled people in the competitive work force. So these arguments about unemployment can also be an excuse! But I think that you're absolutely right about the economic connection.

Dorothy Kerzner-Lipsky"

You know, as you were speaking I was just thinking about those fiscal disincentives that act to prevent disabled individuals from even trying to get into the work force in this country, and we have to be aware of that too. I mean, why should someone go to work and lose their Medicaid if there's a good chance that they'll be laid off nine months down the road? Not just the veterans but also the most severely disabled.

John Agosta

It seems that in the countries that are represented here there is a theme of resistance to change, adoption of a segregated model, and professionalization of services. I heard some people talk this morning in the Cross Cultural Committee meeting and it seems to me that we have a lot to learn from places like China and Korea and Mexico because it seems that they don't have such a structured service system.

Maybe in those countries it is more difficult to get access to services that are required, but I sure as heck hope that in developing their service systems they don't adopt our models that lead to over-specialization and segregation. I think that we have a lot to learn from places where the disabled are cared for more often in families than in institutions.

Carola Murray-Seegert

I agree with you, and hope that through conferences such as this one, through personal exchange of information, and through our publications we can continue this dialogue. Thank you, everyone, for coming.